MDA® 2010 ANNUAL REPORT



Make a Muscle. Make a Difference.®



Message from the President & CEO

The cover of this report reflects a new branding of MDA, and in turn a new era in the Association's development – an era in which a streamlining of our nationwide staff structure and plans for a truncated Labor Day Telethon have us poised for what we foresee as the most dynamic period of advancement MDA has every experienced, in research and service, and in the all-important fundraising effort that enables them. Our new strategy has inspired the support of the greatest cadre of celebrities ever to represent the Association, stars who've been "Making a Muscle and Making a Difference" for MDA in top national media for the past year.

As you'll see in these pages, the increased awareness of our mission that they've spurred has helped achieve dramatic advances despite the effects on the Association of our nation's devastated economy. The Association's research effort forged ahead with both basic and applied biomedical projects and saw several promising treatments move from the laboratory into clinical testing.

Also in 2010, tens of thousands of children and adults received health care services from neuromuscular disease experts at some 200 MDA clinics and 38 MDA/ALS Centers, and nearly 3,500 children attended 80 MDA summer camp sessions.

MDA expanded its use of online media in 2010, providing families with *my*MuscleTeam, a care-coordination tool, and with online educational seminars ("webinars") on topics such as education, travel and medical care. At the same time, social media were integrated into MDA fundraising programs.

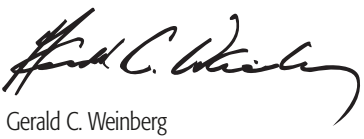
MDA's Advocacy Department supported several initiatives in Washington, D.C., that have the potential to improve the lives of those the Association serves. Among these were collaborations with federal agencies to accelerate research and build clinical trial infrastructure; and support for MDA's National Transitions Initiative, designed to help people with childhood-onset muscle diseases who are now moving into adulthood thanks to decades of MDA support of clinical research and care.

MDA's "Make a Muscle, Make a Difference" campaign surged ahead in 2010 thanks also to support from our national sponsors: Acosta, Bally Total Fitness, CITGO, Clear Channel Radio, ClubCorp, Dr Pepper Snapple Group, ERA Franchise Systems, Harley-Davidson Motor Company, the International Association of Fire Fighters, Lowe's, the National Association of Letter Carriers, National Coalition of 7-Eleven Franchisees, Safeway, and the Tall Cedars of Lebanon of North America.

MDA also launched the Muscle Walk, a new signature fundraising event that brings together MDA families, clinic teams, researchers, camp counselors and sponsors.

"Make a Muscle, Make a Difference" has meant that tough times are falling prey to a toughened Muscular Dystrophy Association, full of dedicated people and supported by loyal sponsors and the public.

With every best wish,



Gerald C. Weinberg

The Make a Muscle, Make a Difference® campaign was created pro bono for MDA by E.B. Lane.



Report from the Chairman of the Board

Whether you call it "bench to bedside," "laboratory to clinic," or "microscope to marketplace," a major emphasis of MDA's research program in 2010 was clear: to move promising treatments through the development pipeline – where possible, all the way to people with neuromuscular diseases.

In amyotrophic lateral sclerosis, that's meant continuing MDA's robust partnership with the ALS Therapy Development Institute (ALS TDI) of Cambridge, Mass., where an experimental compound that modifies the immune system's behavior is a front-runner; continued support of the five-center MDA ALS Clinical Research Network; and funding for Isis Pharmaceutials in Carlsbad, Calif., for development of an innovative drug to block toxic protein synthesis.

In Duchenne and Becker muscular dystrophies, the MDA DMD Clinical Research Network began studies of heart dysfunction and tests of two heart drugs, as well as studies to fill in the gaps about the natural history of DMD in children younger than 3 and young men who are no longer walking. In addition, researchers gained crucial insights into the immunologic barriers to gene therapy in DMD/BMD.

A drug called ataluren, developed by PTC Therapeutics of South Plainfield, N.J., with MDA support, showed promising results in boys with DMD or BMD caused by a certain type of genetic mutation.

Also in 2010, MDA awarded $1.4 million to the biopharmaceutical company Repligen of Waltham, Mass., to develop RG3039, an experimental drug designed to raise levels of a protein that's deficient in spinal muscular atrophy.

MDA funded a number of promising research projects at later stages along the development pipeline while, at the same time, its basic science program continued to feed new ideas into its beginning, ensuring a steady stream of therapeutically focused projects.

Many of MDA's "beginning of the pipeline" grants in 2010 were to seasoned academic researchers holding prestigious posts at major universities. Others were to new entrants into the field, young people with recently minted doctorates in medicine and/or science who are now committed to MDA's goals.

Most of the awards made to projects further along the drug development pipeline have been to biotechnology companies, uniquely positioned to bring innovative drugs to market.

The downturn in the U.S. economy did not change much in 2010, but neither did MDA's unwavering commitment to find treatments for the more than 40 diseases in the Association's program.



R. Rodney Howell, M.D.



Overview of 2010 Operations

Research

Despite the prolonged recession in the U.S. economy, MDA research continued at a rapid pace in 2010. The Association awarded 90 grants for research in the diseases in its program, for a total of more than $33.1 million.

MDA researchers throughout the world continued to explore strategies they've been pursuing and set out in several new directions as well.

Translational research a major focus for MDA

MDA's translational research program took center stage in 2010 in several disease categories. (Translational research seeks to "translate" promising basic science into actual therapies.) Highlights of MDA's translational research achievements in 2010 follow.

DMD and BMD

In 2010, several studies got under way under the auspices of the MDA Duchenne Muscular Dystrophy (DMD) Clinical Research Network. The network consists of five U.S. centers that collaborate on clinical trials and studies designed to improve and standardize care for DMD and the related disease, Becker muscular dystrophy (BMD).

In the fall, the network began studying the natural history of heart function in DMD and BMD, and its correlation to skeletal-muscle function and to specific mutations in the dystrophin gene. Mutations in this gene underlie both DMD and BMD. The network also began a study to compare the effectiveness of the cardiac drugs losartan and lisinopril in DMD.

Late in 2010, the network undertook two additional studies to develop outcome measures for DMD clinical trials in children younger than 3 years old and in boys and young men with DMD who are no longer walking. Most trials in DMD require participants to be old enough to cooperate with strength tests and to be still walking. Being able to measure the effects of experimental treatments in participants who are not in these categories will expand the reach of clinical trials in DMD.

In October, results of a small safety and feasibility trial of dystrophin gene therapy for DMD/BMD were announced and showed that an unwanted immune response to the therapy occurred in some of the participants. In this trial, miniaturized dystrophin genes, encased in viral shells, were injected into the biceps muscles of six participants. These results indicate that immune system rejection of DMD/BMD gene therapy is a factor that deserves major consideration as the field moves forward.

Also in October, New Jersey biotechnology company PTC Therapeutics announced that the low-dose regimen of its experimental drug ataluren increased walking distance in boys with Duchenne muscular dystrophy (DMD) or Becker muscular dystrophy

***"MDA is important for a variety of reasons**, not the least of which is it funds – strategically and knowledgeably – good research."*

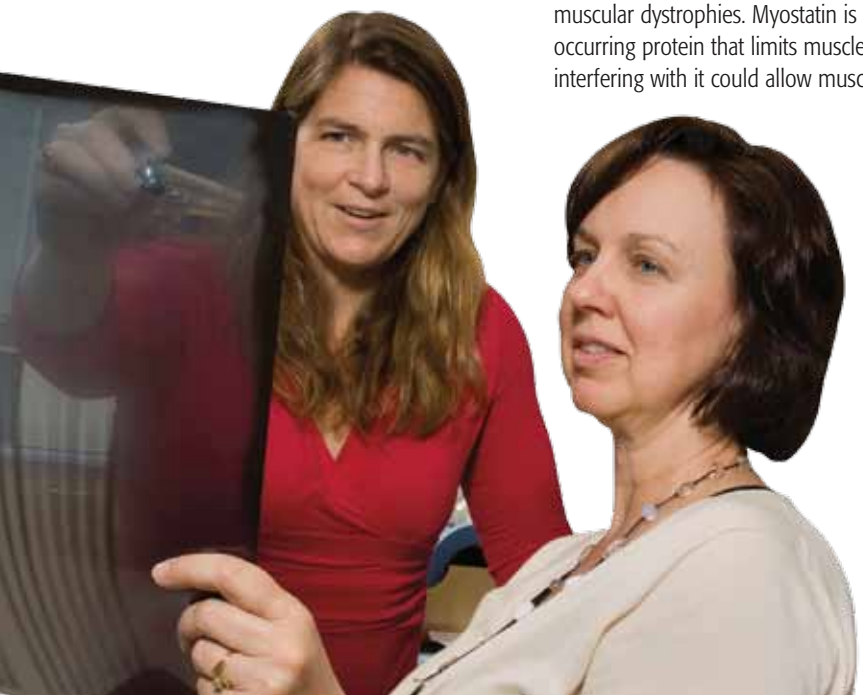
John McCall
Drug discovery consultant
Chair of the spinal muscular atrophy development team
National Institutes of Health

(BMD) who had a certain type of mutation in the dystrophin gene. Ataluren, developed with MDA support to PTC, makes use of a strategy called *stop codon read-through.* It's designed to coax muscle cells to ignore, or "read through," molecular stop signals in the dystrophin gene and produce a functional dystrophin protein.

In April, the multinational pharmaceutical company GlaxoSmithKline and the Dutch biotechnology company Prosensa announced encouraging results from an early-stage trial of their experimental drug PRO051/GSK2402968 in boys with DMD with specific types of dystrophin gene mutations. Eleven of the 12 participants in this trial produced the needed dystrophin protein after treatment with this drug, which is designed to change the way cells read genetic instructions for dystrophin. The drug is a synthetic molecule and makes use of a strategy called *exon skipping*.

The same month, biotechnology company AVI BioPharma of Bothell, Wash., announced similarly encouraging results for its exon-skipping molecule, AVI-4658. MDA funded much of the basic science research that made development of exon-skipping drugs possible.

MDA has supported a strategy called *myostatin inhibition* for DMD, BMD and potentially other muscular dystrophies. Myostatin is a naturally occurring protein that limits muscle growth, and interfering with it could allow muscles to grow



larger and possibly stronger. In 2010, Acceleron Pharma of Cambridge, Mass., began testing the myostatin inhibitor ACE-031 in people with DMD.

Delaware biotechnology company Tivorsan Pharmaceuticals announced in September that it would develop an experimental drug for DMD or BMD based on a protein called biglycan, which had been the subject of MDA-supported research. The goal of biglycan treatment is to improve the structure and function of the muscle-fiber membrane, which is fragile in DMD and BMD because of a deficiency of dystrophin.

Also in 2010, BioMarin Pharmaceutical of Novato, Calif., began testing BMN195 in healthy volunteers. BMN195 is designed to increase production of utrophin, a protein that's very similar to dystrophin and can probably compensate at least partially for the absence of dystrophin. Utrophin research has been a major focus of MDA's basic science program for several years.

ALS

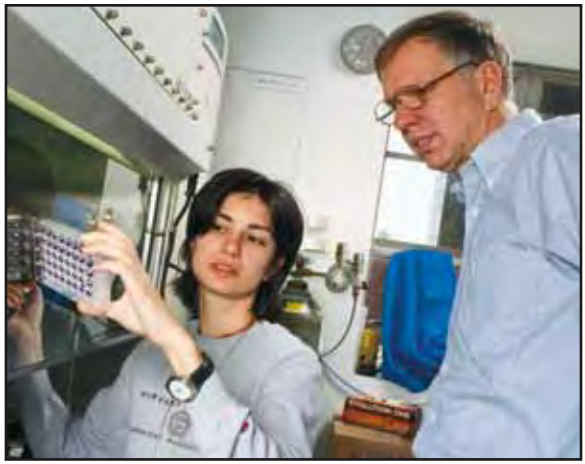
MDA continued its partnership with the ALS Therapy Development Institute (ALS TDI) in Cambridge, Mass., giving the institution a new milestone-driven grant of $2.5 million in January, in addition to the $18 million previously awarded. ALS TDI is a nonprofit research center focused exclusively on developing treatments for ALS.

In 2010, ALS TDI's leading therapeutic candidate was ALS TDI 00846, an immune system modulator.

Also this year, MDA's ALS Clinical Research Network, a consortium of five MDA/ALS centers located throughout the United States, continued to forge ahead. Established by MDA in 2008, each of the five centers in the network receives support from the Association to build infrastructure and conduct clinical trials in ALS (amyotrophic lateral sclerosis). In 2010, a trial to



compare the effects of a regular diet, a high-calorie diet and a high-calorie, high-fat diet in people with ALS continued.



A clinical trial of an experimental drug called ISIS-SOD1-Rx, developed by Isis Pharmaceuticals of Carlsbad, Calif., with MDA support, began in 2010. This is a drug to test a molecular strategy called *antisense*, to see whether it can block genetic instructions for a toxic protein called SOD1 in people with ALS who have mutations in the SOD1 gene. The clinical trial is designed to establish the safety profile of this new compound.

Four other ALS clinical trials, while not directly funded by MDA, were made possible in large part by basic science research conducted by MDA-supported investigators. In 2010, Neuraltus Pharmaceuticals of Palo Alto, Calif., began testing its experimental drug NP001. This small-molecule drug, whose development is based on MDA research on the immune system in ALS, is designed to switch immune system cells from an active, inflammatory mode to a more normal, healing mode in ALS.

Sangamo BioSciences of Richmond, Calif., reported that its experimental compound SB509 was safe and showed hints of possible efficacy in people with ALS. The development of SB509, designed to increase production of a protein called vascular endothelial growth factor (VEGF), benefited from MDA research on this molecule.

Pompe disease

May 2010 saw the approval by the U.S. Food and Drug Administration of Lumizyme, a drug specifically for late-onset Pompe disease (acid maltase enzyme deficiency). Biopharmaceutical company Genzyme of Cambridge, Mass., received approval from the FDA in 2006 to market the closely related drug Myozyme for infants and children with this metabolic muscle disorder. Myozyme and Lumizyme both replace the missing enzyme and were developed in part because of MDA-supported basic science research on acid maltase.

SMA

In December 2010, MDA awarded $1.4 million to the biopharmaceutical company Repligen of Waltham, Mass., for development of RG3039, an experimental drug to treat spinal muscular atrophy (SMA). RG3039 is designed to increase the amount of fully functional SMN protein, which is deficient in people with SMA, by causing cells to process the genetic instructions for SMN in a different way.



Health Care Services

The year 2010 saw enhancements to MDA's program, as well as the continuation of core services.

Tens of thousands of individuals served by MDA received health care services from neuromuscular-disease specialists at some 200 MDA clinics and 38 MDA/ALS centers in the United States and Puerto Rico. Medical experts at MDA clinics conducted medical exams and diagnostic consultations, and made referrals for assistive therapies to help maintain function, independence and quality of life.

MDA clinics are at the forefront of research and clinical care, and the Association is working on many levels to ensure that its clinics continue to meet the needs of those it serves. In 2010, MDA launched an online survey for families seen in MDA clinics called "Tell us about your MDA clinic," as well as a Clinical Advisory Committee comprised of experts in neuromuscular care.

MDA's equipment program provided individuals with nearly 5,500 items of gently used durable medical equipment, from bath equipment and wheelchairs to hospital beds and communication technology, donated by generous and caring individuals. MDA also assisted with repairs to all types of medical equipment for those it serves.

In 2010, nearly 3,500 children ages 6-17 enjoyed a week of fun and friendship through nearly 80 MDA summer camp sessions. More than 4,300 volunteers helped make this week extra special for campers.



"MDA basically means support, *and I think that's clear enough for anybody to understand."*

Benjamin F. Cumbo IV
Graduate student, George Washington University
Duchenne muscular dystrophy

MDA provided a wide range of support programs in 2010. Thousands of individuals and families around the U.S. received help from facilitated MDA support groups, as well as from MDA-sponsored educational seminars; referral services; transitional services for youth with neuromuscular disease who are entering adulthood; online chat sessions and MDA's e-community, *my*MDA.



Two new support options got under way in 2010. *My*MuscleTeam (which actually debuted in December 2009) is an online care coordination tool for families. MDA also launched live expert-hosted webinars on such topics as housing, accessibility, research, medical management, travel, higher education and more. The webinars are archived for viewing on mda.org.

MDA again partnered with Walgreens for its annual flu shot program, providing thousands of free inoculations to individuals served by the Association for whom a "simple case of the flu" could prove life-threatening.





Professional and Public Health Information

MDA takes its health information mission very seriously, providing individuals and families affected by neuromuscular diseases with a wide variety of easy-to-understand information about neuromuscular diseases, current research and health care topics. MDA gears this information to the differing needs of the individuals and families it serves, researchers, health care professionals, the news media and the public at large.

MDA's articulate and passionate spokespeople are another important way MDA spreads the word about the fight against neuromuscular diseases.

Publications

MDA's award-winning Publications program produced a steady stream of print and online information about research and health care, as well as articles about relevant legislation, valuable services and inspiring individuals. In addition to the quarterly Quest magazine and bimonthly MDA/ALS Newsmagazine, the department posted an average of two online news articles a week in 2010, making mda.org the "go-to" site for the latest and most accurate information about neuromuscular disease. MDA's extensive free library of online publications and articles was accessed by individuals affected by muscle diseases in more than 180 countries.

MDA Online

MDA's award-winning website, mda.org, showcased the Association's missions to the world, providing instant information about research, health care services, clinical trials and MDA programs. MDA's Web pages logged more than 7.4 million page views from visitors in 2010. Along with some 100 new projects completed during the year, MDA's Online Services department continued to upgrade MDA's Web infrastructure with more modern and robust technologies.

Television Production

In 2010, MDA's Television Production Division completed a variety of projects for television, radio and other media, including a satellite media tour featuring MDA Chairman of the Board Rod Howell, which highlighted MDA's involvement in the eventual discovery of Myozyme to treat Pompe disease. Educational/informational videos were produced on a number of topics for researchers, families and the general public, and public service announcements featured a variety of celebrities supporting MDA's "Make a Muscle, Make a Difference" multimedia campaign.

MDA Ambassadors

Serving a third term as MDA National Goodwill Ambassador, 11-year-old Abbey Umali, of Redlands, Calif., crisscrossed the country with her parents, speaking from the heart to groups, organizations and large audiences about MDA's quest to defeat muscle diseases. The self-assured and talented 11-year-old has a form of Charcot-Marie-Tooth disease (CMT).

During the 2010 Telethon, Thomas Hale Arrington III, of Chesapeake, Va., was named

*"Every time I visit your site, **I get good information about practically everything**."*

Comment left by a visitor to MDA's website

the 2011 recipient of the Robert Ross MDA National Personal Achievement Award. Arrington, a clean-energy entrepreneur who promotes the use of renewable energy, has facioscapulohumeral muscular dystrophy (FSHD).

Luke Christie of Due West, S.C., served a second term as MDA National Youth Chairman. Luke, who has spinal muscular atrophy, is a former two-time MDA National Goodwill Ambassador (2006 and 2007) and in 2008 was named the first Harley-Davidson MDA Goodwill Ambassador. He turned 17 in 2010.

Augie and Lynne Nieto of Corona del Mar, Calif., served a fifth year as co-chairs of MDA's ALS Division. Augie, who turned 52 in 2010, has lived with ALS since 2005. He continued to be "chief inspiration officer" despite the progression of his disease, speaking via a communication device to organizations and the media about the need to cure ALS. MDA's Augie's Quest is spearheaded by the Nietos, and has raised millions for MDA's fast-track ALS initiative.

Nancy O'Dell, co-anchor of the entertainment news show "Entertainment Tonight," completed her first full year as MDA National ALS Ambassador. O'Dell, who also is a Telethon co-host, spread awareness of MDA's fight against ALS through media interviews, public appearances and public service announcements. In June 2008, ALS claimed the life of O'Dell's mother.



Thomas Hale Arrington III, 2010 Personal Achievement Award recipient

The MDA Art Collection, which represents artists with neuromuscular diseases from every state and Puerto Rico, added six new pieces in 2010. Selections from the more than 370 pieces in the Collection were the subject of gallery and museum shows across the country.

Public Relations

As is evident on the front and back covers of this report, a cadre of celebrities flexed their biceps for MDA's "Make a Muscle, Make a Difference" public service advertising (PSA) campaign, including Reggie Bush, Carrot Top, Don Francisco, Nigel Lythgoe, Kyle Massey, Natalie Morales, Blake Shelton, Alison Sweeney, Triple H, Kurt Warner and Wynonna. PSAs appeared in the Wall Street Journal, USA Today, New York Post, and Time, Parade and Business Traveler magazines, as well as in thousands of TV, cable and radio spots.



Advocacy

MDA's Advocacy Department works year-round to keep the needs of the neuromuscular disease community in the minds of the Washington, D.C., policymakers who craft legislation, research priorities and health policy. The MDA Fly Out – which occurs during the congressional August recess in the representatives' home districts – is just one of the innovative, cost-effective ways MDA enabled the maximum number of individuals and families affected by muscle diseases to make their concerns and priorities known to their legislators in 2010.

MDA's National Task Force on Public Awareness provided insight and guidance to the Association on policy issues and activities of importance to people with disabilities. The 12 professional and community leaders on the Task Force all are affected by neuromuscular diseases, and come from such fields as law, education, homeland security, computer technology, engineering and communications.

Among the many health policy initiatives supported by MDA in 2010 were:

- National Transitions Initiative for MDA community members with pediatric muscle diseases who are transitioning into adulthood
- Collaborations with federal agencies and voluntary health organizations to accelerate research, build critical clinical trial infrastructure, and expand outreach and awareness among medical and patient communities
- SMA Treatment Acceleration Act of 2009
- Medicare Competitive Bidding Repeal Act
- Achieving a Better Life Experience (ABLE) Act

It's through your outstanding work that families and individuals with neuromuscular disease like me ***are living rewarding, productive lives fully integrated into their communities.***

Christopher Rosa
Director, Office of Special Services for Students with Disabilities
Queens College of the City University of New York
Becker muscular dystrophy



Management and Fundraising

For MDA, 2010 was the "Year of Muscle." All our national sponsors rallied around MDA's "Make a Muscle, Make a Difference" campaign. A new MDA signature event was launched in 2010: the MDA Muscle Walk. Billed as MDA's "local family reunion," it brings together individuals and families served by MDA, clinic teams, researchers, camp counselors and MDA sponsors to raise money and participate in a fun, accessible walk. MDA also integrated social media into Lock-Up and Muscle Walk fundraising strategies so that Jailbirds and Muscle Walk participants could use Facebook and Twitter to drive donations to MDA.

The Association began accepting donations by text message, attracting more than $50,000 in new MDA Labor Day Telethon income from people using their cell phones to text "MDA" to 20222.

The 2010 MDA Telethon featured wall-to-wall entertainment, information about research, and profiles of individuals living with muscle diseases, raising $58,919,838 for MDA's missions of help and hope. MDA announced in October that the Telethon will move to a shorter (six-hour) prime-time format in 2011.

After 45 years of dedicated hosting of MDA's signature event, Jerry Lewis announced his retirement as Telethon host, saying "It's time for an all new Telethon era," but also vowing, "I'll never desert MDA and my kids."

In late 2010, MDA dedicated a new 15,000-square-foot building at its national headquarters in Tucson: the Rachel Ann Perkinson Center. The result of a $6 million bequest from the Perkinson estate, the accessible, environmentally friendly building houses MDA's research and health care services programs, and provides much-needed space for meetings and training.



"The thing that MDA has done for me that I am most grateful for is ***they have given me the power to DO something****. If we all* ***do*** *something, I know that we will see the finish line in our battle!"*

Susan Hanna
Muscle Walk participant
Mother of a son with Duchenne muscular dystrophy

Neuromuscular Diseases Included in MDA's Programs

Group/Type	Usual Age of Onset	Disease Characteristics
Muscular Dystrophies		
Myotonic	Birth to adulthood	Weakness of all muscle groups accompanied by delayed relaxation of muscles after contraction. Affects face, feet, hands and neck first. Progression is slow, sometimes spanning 50 to 60 years.
Duchenne	2 to 6 years	General muscle weakness and wasting, affecting pelvis, upper arms and upper legs first. Duchenne progresses slowly, yet eventually involves all voluntary muscles. Survival is rare beyond the late 20s.
Becker	2 to 16 years	Symptoms almost identical to Duchenne yet less severe. Affects pelvis, upper arms and upper legs first. Becker progresses more slowly than Duchenne and survival runs well into middle age.
Limb-Girdle	Late childhood to middle age	Weakness and wasting, affecting shoulder girdle and pelvic girdle first. Disease usually progresses slowly. Variable cardiopulmonary complications may occur in later stages.
Facioscapulohumeral	Childhood to early adulthood	Facial muscle weakness, with weakness and wasting of the shoulders and upper arms. Progressing slowly with some periods of rapid deterioration, disease may span many decades.
Congenital	At birth or infancy	Generalized muscle weakness, with possible joint contractures resulting from shortening of muscles. Disease progresses very slowly. Weakness is variable.
Oculopharyngeal	Early adulthood to middle age	First affects muscles of eyelids and throat. While progression is slow, weakening of throat muscles in time causes swallowing difficulties.
Distal	Early adulthood to middle age	Weakness and wasting of muscles of the hands, forearms and lower legs. Progresses slowly and is rarely life-threatening.
Emery-Dreifuss	Childhood to early teens	Weakness and wasting of shoulder, upper arm and shin muscles. Joint contractures are common. Disease progresses slowly, with cardiac complications common.
Motor Neuron Diseases		
Amyotrophic Lateral Sclerosis (ALS)	Adulthood	Progressive wasting and weakness of all voluntary muscles, with cramps and muscle twitches common. ALS first affects legs, arms and/or throat muscles. Survival rarely exceeds five years after onset, without respiratory intervention.
Infantile Progressive Spinal Muscular Atrophy	Birth to 3 months	Generalized muscle weakness, weak cry, trouble swallowing and sucking, and breathing distress. Life span rarely exceeds age 2.

Group/Type	Usual Age of Onset	Disease Characteristics
Intermediate Spinal Muscular Atrophy	6 months to 3 years	Weakness in arms, legs, upper and lower torso, often with skeletal deformities. Disease progresses rapidly. Respiratory problems can shorten life.
Juvenile Spinal Muscular Atrophy	1 to 15 years	Weakness in leg, hip, shoulder, arm and respiratory muscles. Disease progresses slowly. Life span is unaffected.
Adult Spinal Muscular Atrophy	18 to 50 years	Generalized muscle weakness with muscle twitches common. Disease progression varies.
Spinal-Bulbar Muscular Atrophy	15 to 60 years	Weakness of limb muscles, especially legs, and of muscles involved in talking, chewing and swallowing. Occurs in men. Slowly progressive over decades.
Inflammatory Myopathies		
Polymyositis	Childhood to late adulthood	Weakness of neck and limb muscles, sometimes with pain. Disease severity and progression vary by individual. Sometimes associated with malignancy. Often responds to drug therapy.
Dermatomyositis	Childhood to late adulthood	Weakness of neck and limb muscles, often with pain. Skin rash typically affects cheeks, eyelids, neck, chest and limbs. Disease severity and progression vary. Sometimes associated with malignancy. Often responds to drug therapy.
Inclusion-Body Myositis	After age 50	Weakness of arms, legs and hands, especially thighs, wrists and fingers. Sometimes involves swallowing muscles. Slowly progressive. More common in men than women.
Diseases of the Neuromuscular Junction		
Myasthenia Gravis	Childhood to adulthood	Weakness and fatigability of muscles of the eyes, face, neck, throat, limbs and/or trunk. Weakness may fluctuate. Disease progression varies. Drug therapy and/or removal of thymus gland often effective.
Lambert-Eaton Myasthemic Syndrome	Adulthood	Weakness and fatigue of hip and leg muscles with aching back and thigh muscles common. Lung tumor is often present. Progression varies with success of drug therapy and treatment of any malignancy.
Congenital Myasthenic Syndromes	Infancy or childhood, can be later	Generalized weakness and fatigability of voluntary muscles, including those controlling eye movement, swallowing and breathing. Varies in severity, and weakness can fluctuate.

Neuromuscular Diseases Included in MDA's Programs

Group/Type	Usual Age of Onset	Disease Characteristics
Diseases of the Peripheral Nerves		
Charcot-Marie-Tooth Disease	Childhood to young adulthood	Weakness and atrophy of muscles of hands and lower legs, with foot deformities and some loss of sensation in feet. Disease progression usually slow.
Friedreich's Ataxia	Childhood to adolescence	Impairment of balance and limb coordination, muscle weakness and loss of sensation. Severity and progression of disorder vary. Often associated with diabetes and heart disease.
Dejerine-Sottas Disease	Infancy to early childhood	Delayed development of motor skills. Muscle weakness affects hands and legs and may involve impairment of sensation. Severity and progression of disease vary.
Metabolic Diseases of Muscle		
Phosphorylase Deficiency	Childhood to adolescence	Muscle cramps often occur after exercise. Intense exercise can cause muscle destruction and possible damage to kidneys. Reducing strenuous exercise can lessen severity.
Acid Maltase Deficiency	Infancy to adulthood	For infants, disease is generalized and severe with heart, liver and tongue enlargement common. Adult form involves weakness of upper arms, legs, trunk and respiratory muscles. Progression varies.
Phosphofructokinase Deficiency	Childhood to adulthood	Muscle fatigue which upon exercise can lead to severe cramps, nausea, vomiting, muscle damage and discoloration of urine. Progression varies.
Debrancher Enzyme Deficiency	Early childhood to adulthood	Generalized weakness and muscle wasting. Heart involvement and enlarged liver may occur with infantile form. Episodes of low blood sugar are common. Variable progression. Muscle symptoms may be delayed until teens or adulthood.
Mitochondrial Myopathy	Early childhood to adulthood	Generalized muscle weakness with droopy eyelids and inability to walk. Brain is often involved, with seizures, deafness, loss of balance and vision, and retardation common. Progression and severity vary widely.
Carnitine Deficiency	Early childhood	Varied weakness of shoulder, hip, face and neck muscles. Progression varies and carnitine supplementation can be effective.
Carnitine Palmityl Transferase Deficiency	Young adulthood	Inability to sustain moderate prolonged exercise. Prolonged exercise and/or fasting can cause severe muscle destruction with urine discoloration and kidney damage. Severity varies.
Phosphoglycerate Kinase Deficiency	Childhood to adolescence	Muscle pain and weakness, with muscle damage and urine discoloration possible after vigorous exercise. Severity varies.

Group/Type	Usual Age of Onset	Disease Characteristics
Phosphoglycerate Mutase Deficiency	Childhood to adulthood	Muscular pain, cramps, muscle damage and urine discoloration possible following intense exercise of brief duration. Severity varies.
Lactate Dehydrogenase Deficiency	Childhood to adolescence	Intolerance of intense exercise with muscle damage and urine discoloration possible following strenuous physical activity. Severity of disorder varies.
Myoadenylate Deaminase Deficiency	Early adulthood to middle age	Muscle fatigue and weakness during and after exertion, with muscle soreness or cramping. Condition is nonprogressive and severity varies.
Myopathies Due to Endocrine Abnormalities		
Hyperthyroid Myopathy	Childhood to adulthood	Weakness in upper arm and upper leg muscles with some evidence of wasting. Usually improves with treatment of underlying thyroid condition.
Hypothyroid Myopathy	Childhood to adulthood	Weakness of arm and leg muscles. Stiffness, muscle pain and cramps common. Usually improves with treatment of underlying thyroid condition.
Other Myopathies		
Myotonia Congenita	Early childhood	Muscle stiffness and cramps after periods of rest. Condition causes discomfort but is not life-threatening.
Paramyotonia Congenita	Childhood to early adulthood	Poor or difficult relaxation of muscles, which may worsen after exposure to cold or exercise. Often associated with hyperkalemic periodic paralysis. Condition causes discomfort but isn't life-threatening.
Central Core Disease	Infancy to childhood	Delayed motor development. Hip displacement is not uncommon. Condition can be stable to slowly progressive.
Nemaline Myopathy	Infancy to childhood	Delayed motor development. Weakness of arm, leg, trunk, face and throat muscles. Respiratory involvement common. Severity and progression vary.
Myotubular Myopathy	Infancy	Drooping of upper eyelids, facial weakness. Weakness of the limbs and trunk muscles. Patients almost always have no reflexes. Respiratory involvement is possible. Disease progresses slowly.
Periodic Paralysis – Hypokalemic – Hyperkalemic	Childhood to adulthood	Episodes of generalized muscle weakness. Hyperkalemic type may be associated with paramyotonia congenita. Frequency of attacks and severity vary. May respond to drug therapy.



MDA-Supported Researchers

(For calendar year 2010)

Arizona

Phoenix
St. Joseph's Hospital & Medical Center
Fu-Dong Shi, M.D., Ph.D.

Tempe
Arizona State University
N. Jeanne Wilson-Rawls, Ph.D.

Tucson
University of Arizona
Ronald Allen, Ph.D.
Daniela Zarnescu, Ph.D.

California

Davis
University of California
Gino Cortopassi, Ph.D.
Michael Ferns, Ph.D.
David Richman, M.D.

La Jolla
The Scripps Research Institute
Pritilekha Deka, Ph.D.
Matthew Disney, Ph.D.
Ya Wen Liu, Ph.D.

University of California
Ju Chen, Ph.D.
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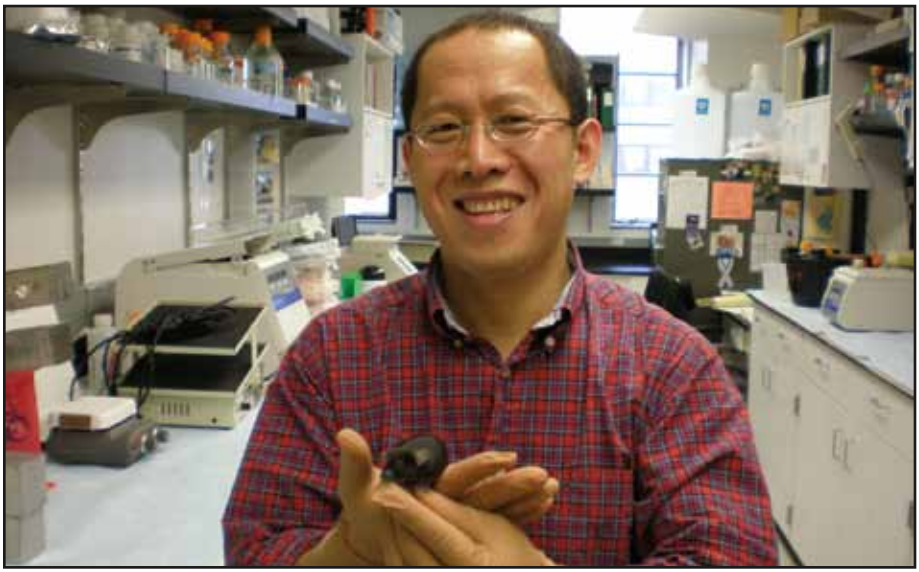
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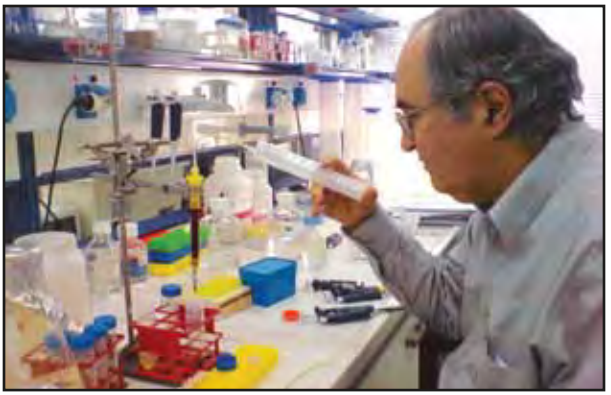
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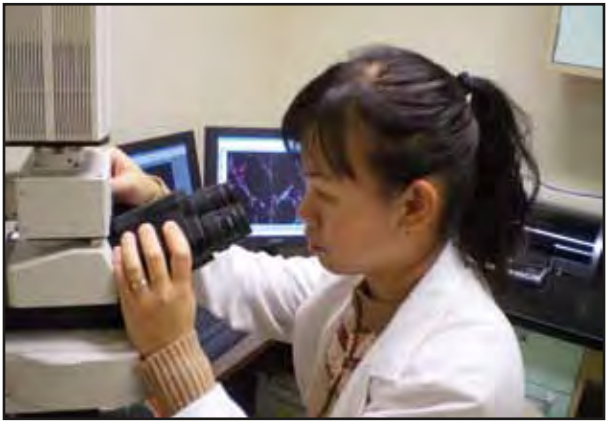
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Rumson, N.J.

Bryan Ward
Pittsburgh, Pa.

Ed Williams
Fairless Hills, Pa.

Ace Young
Sherman Oaks, Calif.

Task Force on Public Awareness

(Members serve one-year terms beginning July 15, 2011)

William W. Altaffer, Esq.
Tucson, Ariz.

Aaron Bates, Esq.
Orlando, Fla.

Jan Blaustone
Nashville, Tenn.

Adnan Gill
Rancho Palos Verdes, Calif.

Nicholas A. Johnson
Waltham, Mass.

Frank Lombardi
Leesburg, Va.

Michael Neufeldt
New Berlin, Wis.

Rob Roozeboom
Sheldon, Iowa

Christopher Rosa, Ph.D.
Flushing, N.Y.

David A. Sheffield, Esq.
Silsbee, Texas

Bradley R. Stephenson, Esq.
San Antonio, Texas

L. Vance Taylor
Oxon Hill, Md.

Angela Wrigglesworth
Houston, Texas



Christopher Rosa, Ph.D.



Report From the Treasurer

Powered by the commitment of our donors, the Muscular Dystrophy Association's research and services programs provided steady beacons of hope to individuals and families affected by neuromuscular diseases in 2010.

The Association spent more than 77 cents of every dollar on program services in 2010. Patient and community services accounted for approximately 43 cents; research, 21 cents; and professional and public health education, 13 cents.

MDA volunteers, sponsors, researchers and staff worked tirelessly to advance the fight against more than 40 forms of muscle disease. Confronted by a weak economy throughout 2010, the Association continued to review and streamline costs, while implementing effective, creative strategies to maintain and enhance the quality of its programs.

The financial statements of MDA for the year ended December 31, 2010, were prepared in accordance with accounting principles generally accepted in the United States for not-for-profit organizations. Ernst & Young LLP, our independent auditors, issued an unqualified opinion on our financial statements. Following are condensed statements of financial position and activities that were derived from our 2010 audited financial statements. For a copy of the complete financial statements and the report of our independent auditors, contact the Finance Department at MDA National Headquarters, 3300 E. Sunrise Drive, Tucson, Arizona, 85718.

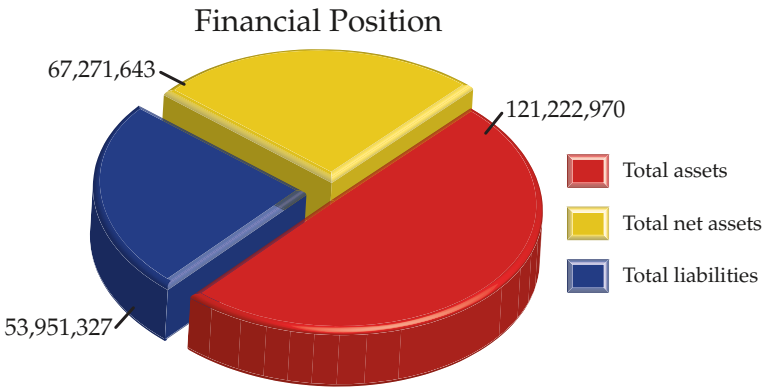


Suzanne Lowden
Treasurer
Muscular Dystrophy Association
July 16, 2011

Statement of Financial Position

December 31, 2010

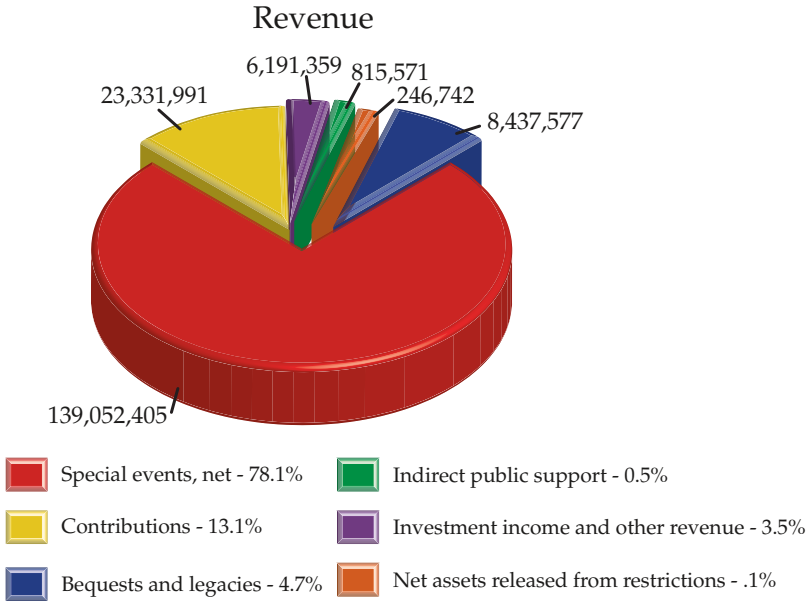
Assets	
Cash and cash equivalents	$ 21,809,108
Contributions receivable, net of allowance for doubtful accounts of $450,000	5,917,002
Prepaid expenses and other assets	3,158,123
Investments	75,354,127
Fixed assets, net	14,984,610
Total assets	$ 121,222,970
Liabilities and net assets	
Liabilities:	
Accounts payable and accrued expenses	$ 7,779,948
Research awards, grants and fellowships payable	26,132,145
Pension and post-retirement plan obligations	20,039,234
Total liabilities	53,951,327
Net assets:	
Unrestricted:	
Available for program and supporting services	51,129,412
Net investment in fixed assets	14,984,610
Temporary restricted	1,157,621
Total net assets	67,271,643
Total liabilities and net assets	$ 121,222,970



Statement of Activities – Revenue

Year Ended December 31, 2010

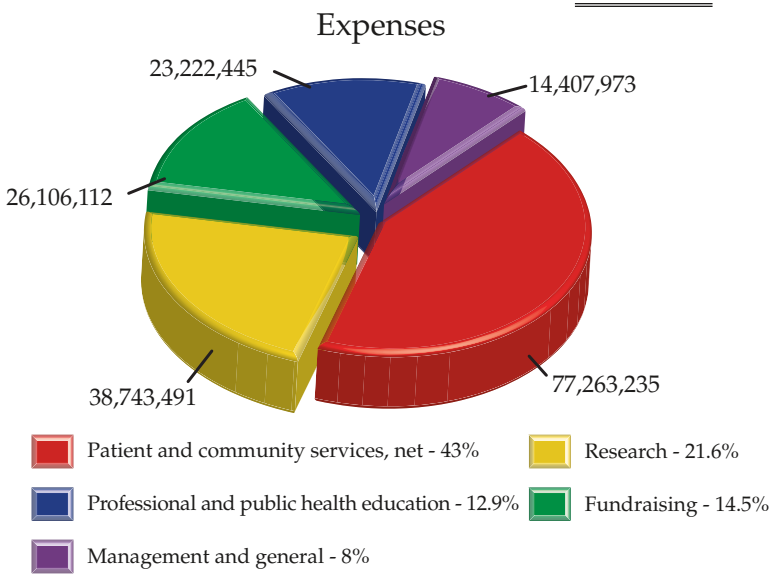
Public support:	
Received directly:	
Special events, including Telethon	$ 173,367,689
Less fundraising direct benefit costs	(34,315,284)
Special events, net	139,052,405
Contributions	23,331,991
Bequests and legacies	8,437,577
Total received directly	170,821,973
Received indirectly:	
Combined Federal Campaign and Combined Health Appeals	815,571
Total revenue from the public	171,637,544
Investment income and other revenue	6,191,359
Total unrestricted revenue	$ 177,828,903
Net assets release from restrictions	246,742
Total unrestricted revenue and support	$ 178,075,645



Statement of Activities – Expenses

Year Ended December 31, 2010

Program services:	
Patient and community services, net of third-party reimbursements of $854,570	$ 77,263,235
Research	38,743,491
Professional and public health education	23,222,445
Total program services	139,229,171
Supporting services:	
Fundraising	26,106,112
Management and general	14,407,973
Total supporting services	40,514,085
Total expenses	179,743,256
Decrease in unrestricted net assets from operations	(1,667,611)
Changes in unrecognized benefit plan costs	(5,314,996)
Decrease in unrestricted net assets	(6,982,607)
Net assets released from restrictions	(246,742)
Decrease in net assets	(7,229,349)
Net assets, beginning of year	74,500,992
Net assets, end of year	$ 67,271,643



Join Our Muscle Team®!



From left: Booboo Stewart, Charo, Kurt Warner, Wynonna Judd, Abbey Umali, Jann Carl, Darius Rucker, Brandon Barash and Nancy O'Dell

Make a Muscle Make a Difference®

Put your muscle, your strength and your commitment behind MDA.

Together, we can provide hope, help and greater understanding in the fight against the muscle diseases that affect children and adults.

Be the next to flex, the next to join in the fight.



From left: Alison Sweeney, Triple H, Nadia Comaneci & Bart Conner, Ace Young, Terry Fator, Mario Kreutzberger ("Don Francisco"), Natalie Morales and Nigel Lythgoe

(800) 572-1717
www.mda.org

MDA® Muscular Dystrophy Association

MDA Muscle Team campaign created pro bono by E.B. Lane with media placement by TargetCast tcm

MDA® Muscular Dystrophy Association

Fighting Muscle Disease



Make a Muscle. Make a Difference.®

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